

## Saving Babies

Beginning tomorrow, Uncle Sam will be looking over the shoulders of America's baby doctors. A new Department of Health and Human Services rule will require hospitals to provide adequate nutrition and medical treatment to newly born infants with extremely serious medical problems. A hospital found derelict could lose its federal funds. The rule is being imposed because the government believes more doctors and parents are withholding treatment from infants with serious but possibly treatable birth defects. The most controversial and best-known case involved a baby in Bloomington, Ind., born with Down's syndrome and a blocked esophagus. Its parents and an attending physician decided to withhold nutrition until the infant died, and a local court affirmed that decision. President Reagan became concerned and ordered HHS to do something about it.

Putting aside for a moment the merits of the rule itself, it is very likely to set off a wide debate over the treatment of gravely ill newborns. Those already involved can attest to profound ethical dilemmas regarding proper use of rapidly developing technologies. To what extent should decisions to save or sacrifice an endangered infant's life rely on the judgment of attending physicians, and what are their criteria for making such decisions? What is the proper role of parents in this process? What is the proper role of the law? Finally, very serious questions have been raised about how a society maintains its moral bearings as it seeks the benefits of its own scientific advancements. It's also worth keeping in mind the real subject of all this heavy thinking: One of us who has just been born is lying in a nursery and is in a lot of trouble.

Let's consider how the endangered-infant rule is to work. It's actually an extension of the 1973 law preventing discrimination against handicapped persons. Every hospital ward must now post a sign reading in part: "Any person having knowledge that a handicapped infant is being discriminatorily denied food or customary medical care should immediately contact the Handicapped Infant Hotline." This "hotline" is an 800 number that will ring at HHS in Washington 24 hours a day. HHS will call its regional Office for Civil Rights, which will dispatch directly to the hospital either its own investigator or someone from a local child protective agency. The rationale for this aggressive procedure is that hours are important to a newborn who, the department says, "is being discriminatorily denied nutrition." What this last refers to is the decision made in Bloomington and in several other controversial cases. Some advocates of the HHS rule, notably Surgeon General C. Everett Koop, argue that what they call "passive euthanasia," or unjustifiably letting disabled infants die, is more widespread in

hospital nurseries than commonly thought.

They further argue that well-educated parents are increasingly anxious about having an imperfect child who will impair their or the child's "quality of life." This pressure, Dr. Koop and others believe, lays the groundwork for a social consensus that slowly widens the categories of infant "imperfectibility" deemed permissible for withholding medical treatment. A common reaction to this sort of thinking is to dismiss it as extreme, but based on many of the behavioral, social and educational ideas we've been expected to ratify as harmless the past 15 years, we think one would be more than a little wide-eyed not to take Dr. Koop's concerns seriously.

But though the HHS rule may serve the useful purpose of forcing us to face these issues, we doubt it will provide infants the saving hand its advocates intend. For example, medicine cannot yet repair a baby born without brain function or with extremely low birth weight, and maximum care is not warranted. An HHS lawyer might say its warning reflects this, but distraught parents may be in no mood for legal nuance. The hotline's stern warning suggests that doctors aren't to be trusted, and it is likely that some parents will use it to demand that the federal government corroborate their doctor's fatal diagnosis.

Moreover, an aggressive federal intervention will probably push the issue into the two arenas where nearly everyone concerned agrees it shouldn't be—in court or in Congress. Either would most likely set the physician's art in the wet cement of a public law. Before turning the lawyers loose on the nurseries, we might consider that these pediatricians and neonatologists are the same people who developed many of the lifesaving techniques now forcing us to create decision-making mechanisms that reflect a similar high intelligence. Some doctors are themselves calling for clearer procedural criteria in dealing with these tough calls, and some hospitals have set up local review boards to handle gray-area cases. As to the need for the protection of law, we have little doubt that a case will be brought to test the efficacy of these evolving local procedures. Surely this would be a more prudent use of the court function than asking a judge to design medical procedures.

By urging HHS to take immediate action, Mr. Reagan has signaled his concern that life-and-death decisions at the point of birth in this country are to be taken with the most serious respect for human life. That's to be commended but we hope federal regulators will tread carefully in this area, and that they will now work with the medical community to develop a more sophisticated alternative to their hotline. It would be a shame if their intervention proved more harmful than beneficial to human life.